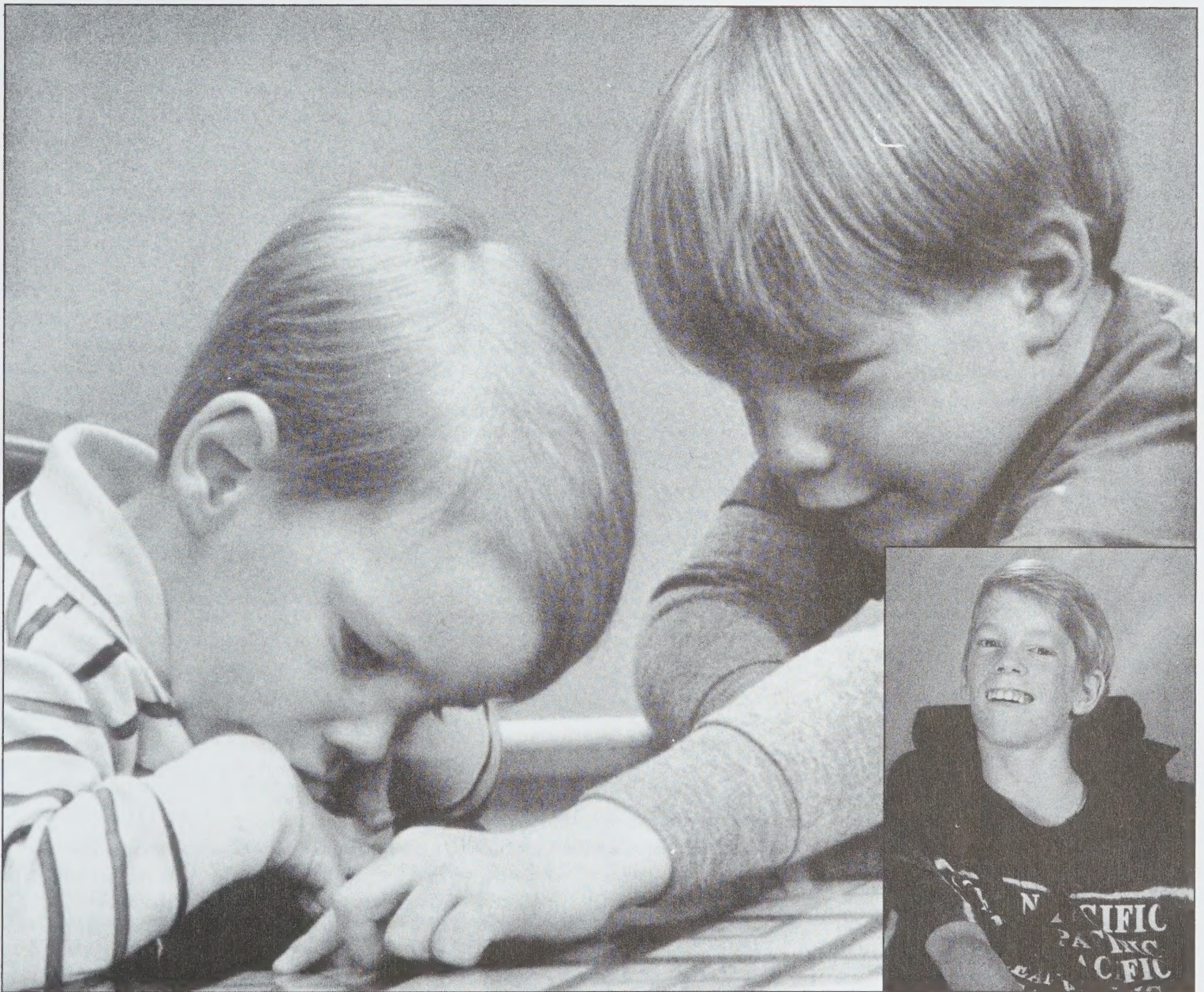


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AS ABILITIES CHANGE

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Change!

SHIRLEY McNAUGHTON



Shirley McNaughton

We apologize for the extreme lateness of this issue of **Communicating Together**. In coming to press, we have greatly missed the key involvement of Peter Lindsay. Peter is having to take things easy while he works through some serious health problems. It has not been easy to fill in for him! All the editors wish him a speedy return to full health and to participation in the many projects to which he contributes so much!

The theme for this issue is *Change*. After fifteen years of publishing **Communicating Together**, we felt we should look back and consider *change*, from the perspective of our editorial team. As well, we asked Ann Kennedy, who served as editor of the magazine from 1982 to 1991, to share her memories. We appreciate her writing the feature article for this anniversary issue!

The magazine began in 1982 when Ann Kennedy and I were both associated with Blissymbolics Communication International. It originally served as a means of sharing information about Blissymbols and those who use them. We quickly found that persons in the expanding field of augmentative and alternative communication (AAC) needed a broader area of coverage, so we began focussing on graphics of all kinds. Technology was always included, but was never the dominant topic. When the Easter Seal Communication Institute (ESCI) was established in the mid eighties, **Communicating Together** became a part of its mandate. For a short time, a centre-insert entitled *Communicating in Ontario* was added. In 1991, when, due to cutbacks, it was decided that ESCI could no longer produce the magazine, Peter Lindsay and I were given the opportunity to take on the production of the magazine. We established Sharing to Learn and gathered around us a wonderful team of associate editors.

Other than the addition of associate editors, the major differences beginning in 1992 were the adopting of themes for each issue and the planning of the years' four themes each spring at an associate editors' weekend retreat. Other innovations have been a section relating to acquired communication impairments and,

just this year, the addition of ComTog Online. Prior to 1992, Ann Kennedy had the responsibility of collecting all the articles for each issue — and a sizable task it was! Ann has been kind enough to refrain from mentioning that since 1992 it has taken nine of us to accomplish the work she undertook single-handed throughout the eighties!

Ann Kennedy's looking back stimulated many memories for me. The contribution of AAC users in writing articles was evident right from the beginning, and we have continued the tradition in recent years with two AAC users serving as associate editors and others contributing articles from time to time. It is interesting that we have fewer "how to" articles these days. In the early days, **Communicating Together** filled a gap that no longer exists, now that there are texts, manuals, software programs, ISAAC and the AAC journal to support AAC usage.

In this reflective issue, Colleen McGaffey has shared a view of institutions that considers the valuable contribution *enlightened* institutions in the nineties can make for some individuals. We need reminding of the different but still positive ways of responding to the needs of persons with disabilities.

Tracy Shepherd's interviews with parents of AAC users growing up in different decades provide many insights.

Repeatedly, the conflict between providing the best in communication and meeting the realities of everyday life was emphasized.

One cannot read this issue without being struck by the impact that cutbacks are having on AAC users. Parents are being asked to do even more, inadequate technology is more difficult to replace, educational programs are being closed. (See Suzanne Clancy's article.) We hope you will share your copies of **Communicating Together** and other sources of information regarding the needs and accomplishments of AAC users with those who are in a position to lobby on their behalf. Many of us feel that we have returned to the sixties!

For a magazine not focussed on technology, it is interesting to note how much attention technology has received in this anniversary issue. Geb Verburg, Paul Marshall, Tracy Shepherd, Nola Millin, all refer to it as they look back over the years. The impact of technology upon AAC has been tremendous. Hopefully, we will continue to benefit from it, but also learn to live with it, not be controlled by it. There will be more to come in December when the theme is technology and our use of it.

As is often the case, Geb Verburg's article stimulates much thought — this time, from his comparison of AAC and seating. Having been involved as an AAC professional throughout the era of technological and societal change discussed by

Geb, I wish to comment on both the similarities *and* differences between AAC and seating. Their *similarities* include their strong and all pervasive effect upon the individual's total functioning, their need for the combined expertise of several disciplines, and their need for time. And, both are influenced by changes in technology.

Several *differences*, however, must be acknowledged — the visibility of the individual's seating system contrasted with his or her communication potential, the relative ease in which mistakes in seating can be identified contrasted with errors in a communication system, the individual's ability with regard to seating to say, "Stop, this is not working! I'm not comfortable in my back, leg, etc." contrasted with questioning or troubled eyes, when a communication system is not working. Whenever an inappropriate seating solution has been provided, it should be quickly evident from the person's poor positioning and appearance, their discomfort and their inability to function combined with their ability to *say* what is wrong. Contrast this with an inappropriate communication solution! The effects may not be discovered for years, if ever. The vocabulary that was not acquired, the language that was not developed, the problem solving and cognitive strategies that were not facilitated, the literacy level that was not achieved, will never be known.

The time limitations, the caseload pressures and the large class sizes that prevent AAC

professionals from evaluating change and resisting those elements that are not positive are truly distressing. Many individuals with severe communication impairments cannot "discuss with the specialists" how their communication can be improved! They need the caring, thoughtful help and *time* of family and specialists working together.

I hope this issue will lead you to reflect upon changes you have observed in AAC. It is important to weigh Geb Verburg's points regarding the trend toward Off-the-Shelf solutions, Paul Marshall's admonitions against being trapped by new technology, Tracy Shepherd's concern re parent burnout, Suzanne Clancy's discouragement regarding current societal and political attitudes, against the positive changes identified in the sections by Nola Millin, Colleen McGaffey and Alda Steprans. Change is never one-sided. We need to look carefully at the effects of change upon the family and be ready to acknowledge that the newest is not always the best! What seems most striking is our inability to deal with change — to foster and build on the good and to discard the bad. Let's hope we become much better during the next fifteen years at intervening when change is not beneficial. Let's begin by acknowledging that no matter how strongly we desire simple solutions, human development and human behaviour are complex!

§

The Early Days: Communicating Together

ANN KENNEDY



Ann Kennedy

When Shirley asked me to write for this 15th anniversary of **Communicating Together**, I had no idea I would spend hours immersed in memories and the past as I pored over the first ten volumes, 1982-1991, in which I was first managing editor and then editor. Reminiscences of events, people, and ideas came rushing back. In choosing highlights for this article, I agonized in selecting what to mention, but here are a few I especially remember.

One of the most vivid memories I have is walking excitedly into the exhibit room at the Second International Nonspeech Conference at the Ontario Institute for Studies in Education in Toronto in 1982 with an armful of "hot -off-the-press" inaugural issues with a front cover of Ann Running, and Kari Harrington, printed in a ghastly shade of orange. There

had been a "communication error" between our graphic designer and the printer. I was so glad it got there in time for the conference, however, that I even overlooked the colour!

For me, the most exciting and moving story over those years was that of Justin Clark in Volume 1, #2. Justin had just won a significant court battle in which he was found mentally competent, and hence had the right to choose where and how he would reside. He had lived in the Rideau Regional Centre for the Mentally Retarded from the time he was two years old. At age 18, and against the wishes of his parents he wanted to leave the institution to live in a group home. This case was the first one in Canadian history in which Blissymbols were used by a witness to give testimony. At the end of the trial, Judge Matheson challenged Canadians to look beyond an individual's physical disabilities to his or her total capacity for learning and development. Three years later, (Vol. 3, No. 1) Justin was once again our feature story, after he and seven members from his community group home made a month long trip to Europe. It was a masterful job of planning, adaptation and execution to ensure the group traveled comfortably and with minimal difficulty in airplanes and in getting through customs. They travelled in Germany, France, Alsace, and Switzerland,

and along the way visited many family and friends. They camped in tents, stayed in monasteries and youth hostels and generally had a marvelous time wherever they went.

Another "camping" story I found memorable was that of Andrew Murphy's Wilderness Adventure (Vol. 5, No. 4). Though he was at first enthusiastic about the idea, Andrew grew somewhat apprehensive as the time drew closer for his eight day camping trip in northern Minnesota. As soon as he met his group leader, his fears were set to rest. He had a fantastic canoe trip, and with a superb team of group leaders supporting and encouraging him, he participated in the canoeing, portaging, "swamping" of the canoes, and nightly campfires and activities.

Over the ten years, there were many regulars who wrote on a quarterly basis for us. I hesitate to mention them by name, at the risk of leaving some out, but some became close friends throughout the years. As is still the case, we had regular columns right from the first issue. Two columns with ongoing writers were *Sharing Ideas with Nora* in which Nora Rothschild, AAC clinician at the Hugh MacMillan Rehabilitation Centre (now the Bloorview MacMillan Centre) answered questions from readers, and gave tips about programming for nonspeaking students. There were many "bon mots" in the

advice she gave over the first four years.

Another early writer who is still actively involved with **Communicating Together** is Geb Verberg from the Bloorview MacMillan Centre. Originally he authored the section *Research and Publications*. He now authors *Contexts*. Editing his columns was frequently challenging. I was always asking: "What do you really mean, Geb? Remember you are writing for the average guy like me." But it was always fun. I found he had a great sense of humour. Even if you didn't always agree with him, Geb provided much food for thought.

For the first five years, the editor of our *Family and Community* section was Andrew Murphy, assisted by his father, Mark. We became close friends over those years, as he wrote about a variety of personal experiences, from trips with his family to heading off to a regular school after he moved to Florida. He also corresponded with many other consumers, and told their stories in the column too. I was greatly saddened by Andrew's untimely death in 1994.

Another consumer who became a close friend was Kari Harrington, who followed Andrew as editor of *Family and Community*. She brought her own perspective, and wrote of her feelings as she underwent major surgery, moved out on her own into a residence after twenty years at home, and learned to cope with the many challenges she met. Kari has a great gift for poetry and has shared several of her poems in her column over the years.

The columns *Perspectives, Teaching and Learning* and *Augmentative Communication* gave us the opportunity to interview both leaders and newcomers in the developing field of AAC. Well known professionals such as Lyle Lloyd gave us his thoughts on a definition of "nonspeaking" (Vol. 2, No. 1). In 1983, Andrea Blau wrote an article on "Interaction". This was followed the next issue with a follow-up article "More on Interaction" by a newcomer at the time, Janice Light (Vol. 2, No. 1). It is interesting that these are topics still being discussed years later.

Over the years we had many classroom teachers submit "How To" articles giving valuable programming suggestions, and examples of useful teaching aids and toys that teachers could use in their own classes. At that time, unlike today, there were few ready-made materials or manuals available for teachers and speech language pathologists. Other articles such as those by Barbara Rush in Hamilton Ontario discussing total communication ideas in her classroom (Vol. 1, No. 2), Anne Warrick with ideas for adapting and using toys (Vol. 4, No. 4 & Vol. 5, No.1) and Caroline Musselwhite with suggestions for Augmentative Music; Symbol Aided Singing (Vol. 3, No. 4) helped those teachers who were encountering nonspeaking students in their classes for the first time.

My list of those who willingly shared their knowledge with us could go on and on. People such as David Yoder, Bruce

Baker, Barry Romich, Howard Shane, Faith Carlson and many others took time to write for us. As the field of AAC expanded, so did contact with those from outside North America. We have learned much from our writers about the growth of AAC around the world. There have been articles from India, Poland, Israel, Hungary, the Nordic countries, to name but a few. Many of these authors have become good friends through ISAAC or Blissymbolics Communication International Affiliate meetings.

There have been many memorable events over the last fifteen years that we have written about. In hindsight, the short article in the summer issue of 1983, announcing the birth of ISAAC was one of the most significant events. Who would have guessed how this organization would grow internationally from that time to the present!

For me, many of the significant events since then have revolved around ISAAC meetings. One highlight is my memory of the trip to Disneyland in California (Vol. 6, No. 4) when I wrote about the adventure of accompanying a group four nonspeaking young people to the Fifth Biennial ISAAC conference. In our group we had John Dowling, Kari Harrington, Ann Running and Susan Odell, all consumers experienced in making presentations to community organizations and schools. This was the first conference that featured a "Consumer Day", and our group were active participants in it. We experienced first hand many of the frustrations and hardships of the consumers as

we dealt with electric chairs that broke down, taxis that didn't appear and numerous other irritants of travel that are minor inconveniences for the able-bodied, and tremendous hurdles for those in wheelchairs. However, even these challenges could not dampen our enthusiasm.

Another significant event that greatly affected the production of **Communicating Together** was the development of a typesetting font for Blissymbols by our production and printing house, Beacon Herald Fine Printing of Stratford, Ontario. The folks there had become interested in Blissymbols and felt they could produce a typesetting font that would replace our archaic "cut and paste" method of inserting symbols into text (Vol. 2, No. 4). This technology, that was to become invaluable in the publication of *Communicating with Blissymbolics* and the *Independent Study Guide* is now essentially obsolete. The AccessBliss software program for the Macintosh computer released in 1990

has made inclusion of Blissymbols in desktop publishing so simple. (*Editor's note: The current challenge being tackled by Paul Marshall is the production of Blissymbols on the Blissymbolics Communication International website.*) Technology continued to develop at an amazing rate during the last decade, for example BlissTel, released in 1990 (Vol. 8, No. 3). This program, developed by the IDON Corp. in Ottawa with a grant from Dept of Communications, Government of Canada, allowed Bliss users to communicate in Blissymbols for the first time via modem and a telephone bulletin board system (BBS) — one more tool to move consumers to greater independence. (*Editor's note: This software has been superseded first by BlissNet and then by BlissInternet.*)

As years passed, I noticed more consumer stories. In the early years, the articles were often written about

consumers. Now they are more often submitted by consumers themselves — a healthy development that surely speaks for the coming of age of consumer independence. Technology, too, has changed dramatically. In 1982, we were impressed when students could use an Apple computer for communication. Now the choices of high tech communication devices is staggering. Synthetic speech has reached levels of clarity we never would have thought possible fifteen years ago. In June of 1984, I attended the ICRE II (International Congress of Rehabilitation Engineers) joint meeting with RESNA (Rehabilitation Engineering Society of North America) in Ottawa and reported in **Communicating Together** as follows: "Wheelchairs and white canes were commonplace around Ottawa that week. However, I saw few communication aid users and look forward to future years to more nonspeaking people participating actively in such conferences." Fifteen years later, their participation is an accepted fact. §

AAC: AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

*The Official Journal of the
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Editor: **David R. Beukelman**, Professor of Communication Disorders,
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Communicating Now and Then

TRACY SHEPHERD



Tracy Shepherd

Communicating Together has now been in publication for fifteen years. Congratulations! How have things changed in the area of Augmentative and Alternative Communication(AAC)? I will focus on the family and how AAC has changed for them. My approach has been to interview families who have children at varying ages to get a sense of how things are now and how they have evolved over the last 15 years.

The 90's Families

I approached families who have young children between three and six years of age to get their perspective having just begun AAC in the 90's. Samantha Millar of Newmarket, Ontario turned four years old in August. She is involved with a very enthusiastic team that is committed to teaching her

Blissymbolics to augment her communication.

Samantha was diagnosed with athetoid cerebral palsy at ten months of age. Her sister Jayme is fifteen months old and, as Cal their father explains, they are beginning to learn expressive language at the same time. Samantha, of course, is three years ahead in receptive language skills. Samantha was first seen by the Augmentative Communication Service (ACS) of the Bloorview MacMillan Centre when she was two years old. She began to use computers and an eye gaze system to communicate at this very young age. She is currently learning to scan with a head switch. As Cal explains, the team expects that Samantha will be quite literate one day as she is already starting to recognize words from memory. This led them to break the trend at ACS to use picture symbols for beginning communication. The family felt Blissymbols would provide Samantha with more language learning opportunities and facilitate her progression into traditional orthography. She is doing wonderfully well at using an eye gaze board with a two-step encoding process. And she only just turned four!

Samantha has been tremendously fortunate to have enlisted a team to help in the teaching and learning of Blissymbols. It has not been

without its struggles as Julie, Samantha's mother pointed out. Blissymbols have not been as frequently used in North America in the recent past as they had been several years ago. Samantha has the support of several former Bliss users including Paul Marshall to help with some of the questions and concerns. Julie explains that without Shirley McNaughton's help they would not have been able to carry out this program. They at times have found it difficult and feel that professionals have placed a lot of expectations on them. It is up to Julie and Cal to teach Samantha the symbol system and Julie worries that they may not be doing it right. There is so much involved in learning symbols, doing therapy, going to school and just being a four-year-old girl. Julie is learning to make the Blissboards and admits that it is time consuming and frustrating. Developing vocabulary is another struggle with which she feels she would like some support. Although I talked to Julie on a "frustrating day" she still felt that Bliss was of benefit to Samantha. They certainly have no regrets and know that Blissymbolics is the right system for Samantha. Julie just felt there are a lot of demands placed on parents and often not enough direction to make them feel confident enough in carrying them out. Recently, after less than two months with her Blissymbol board, Samantha

produced her first three-symbol utterance upon seeing a woman in an electrical wheelchair at a seating clinic: "how + wheelchair + go?" Moments like this make all the work seem worthwhile! Julie and Cal were both very excited!

I talked with a foster parent who has had experiences with several children with disabilities with varying levels of communication abilities. Cindy Lebreque of Amhurstburg Ontario, told me until the very recent past the children they have fostered have not had the opportunity of voice output devices. It wasn't until three years ago that they had the great pleasure of having six-year-old Kelly in their home. Cindy was eager to investigate technology for communicating as soon as she found out about its availability. Until Kelly was provided with a system, the family made do with signing and various signals that they had worked out in the home for Kelly to gain attention. Kelly has a tracheotomy and is completely non-verbal. Her health is a tremendous concern and the introduction of voice output has helped put the family at ease. Kelly is now able to call for help from the other room rather than just banging on the floor or ringing a bell. It is now safer for her to be out of sight. Cindy describes that it has taken Kelly a while to internalize the use of the talker and to realize that it is "her" voice and it is a part of her. Since voice output was introduced, her life has completely changed. The most

important thing for Kelly is that she has a voice now.

One of my favourite Kelly stories goes like this: Her mom and dad were talking and having an important conversation. Kelly kept trying to interrupt (as most four or five-year-olds would try to do to get attention). Kelly was trying signing, she was trying gesturing, she was trying banging the floor. Nothing was working! Kelly then realized she had another method (her voice output device was fairly new to her at the time). She went looking for her talker. It was located on a table slightly taller than her but she could just reach the handle. So she did! She grabbed the handle and pulled it and *bang!* You know, I really think it is a success story to hear of a child seeking out and using the technology provided to her. Even if it meant we had a few repairs to make as a result.

Families from the Middle Years

The next families I contacted were those who have teenagers and young adults. I wanted to see if things were different for them and if they could identify any changes. Susan Barnard of Hamilton has a son Scott who is 21 years old and is mentally challenged. Scott is currently still in high school and is communicating using a 900 symbol Blissboard. The professionals initially didn't feel that he would be able to learn Bliss but as his mom said, "He took to it like a duck to water." He is also using Bliss to write and is able to compose sentences using Bliss at the computer.

Susan cannot say enough good things about AAC and the positive effects it had on Scott and the family. When he was quite small the only way he could communicate his wants and needs was to cry. Susan describes the heartbreak in seeing her child cry and not being able to interpret what he wanted. Scott began using signs and when he learned his first sign "more" his world began to open up. She finds now he is using many modes of communication. She is no longer guessing and the use of AAC has eliminated the frustration in Scott, and in Sue herself. She now knows what he is trying to get across and he doesn't have to cry.

Keith Spencer of Markham, Ontario first wrote for **Communicating Together** in 1983. Our front cover for this issue shows the picture of Keith's twin sons as they appeared on the cover of the Spring, 1983 issue, along with Andrew as he looks today. The 1983 article was written when the twins, Andrew and Jason, were only four years old and Keith and his wife, Margaret, were involved with many organizations and agencies.

Andrew was born with cerebral palsy and was a pioneer for new equipment being introduced in the 80's. Andrew communicates with a Blissboard and book. Keith explains that he mostly has the positions on the boards memorized and as they add new vocabulary they tend to use text only. For

communication, Bliss has been the mainstay and continues to be his primary mode. Andrew can quickly eye point to his Bliss board to have a conversation. Andrew has a computer at home which he is able to access with a head switch and a very laborious slow scan. It is not surprising he doesn't use it very often. It requires too much work and takes too much time for too little pay-off.

Keith describes Andrew as very expressive, intelligent and dependent. Now, as a teenager they find it "doesn't get any easier." In fact, they have to spend more time now that Andrew is in high school. Helping him complete his homework is quite time consuming particularly when working on topics like Romeo and Juliet. They find the support is less and they have a hard time finding more adult type activities in which Andrew can participate. Andrew has several friends at school (his dad points out that they are mostly girls. Way to go Andrew!). When asked if they had thought about what Andrew will do when he gets out of high school the response was that they start to think about it and then they just stop. They find it best to take each day as it comes.

Regarding professionals, the Spencers have found that over the years they have become more and more withdrawn. Margaret and Keith feel that this may be due to budgetary constraints. They feel that even the professionals get burned out and start to repeat the same old platitudes. Some of the

relationships with professionals have been a difficult struggle. Keith feels as though professionals have lost touch with the pragmatic realities of daily life. If it takes Andrew eight hours to write a short thank-you note, how can that be rewarding or motivating for him to continue? It was interesting that Keith said, as a field to work in, it would be great to see the advancements and changes, but as a family that just wants to get on with life it is of little help. The problem continues to be finding time to do all the extras in the busy family life of the 90's — there just isn't the time! Keith says, to be quite honest, they are tired of advocating and they don't have the energy they once did. The biggest change this family has experienced is burnout.

I was tremendously impressed with the honesty of Keith Spencer. He spoke from his heart saying they had done everything they could when Andrew was young and by the time he was about ten they just couldn't keep it up anymore.

The Families from Many Years Ago

These families have seen the evolution of the field of AAC from the ground up. They bring tremendous insights! Donna Joslin and her children have been an inspiration to me for many years. Donna is the single parent of four young adults. She has written for **Communicating Together** previously in June 1996 for the *Families and Parenting* issue. Angel and Amy, her adopted daughters, are both

nonspeaking and depend on their communication devices to survive. They are both in their mid-twenties. When I talked to Donna she explained that when she first adopted the girls there was little in the way of augmentative communication.

Donna is not a stranger to computers and technology. Like the rest of us, she marvels at all that continues to be developed. The problem, particularly for individuals with disabilities, is that as these advancements are made, the market driving the changes continues to force the prices up. Specifically, devices dedicated to voice output are so highly priced that computer-based systems are starting to get more use for voice output. (This will be a topic for another issue. Stay tuned for **Communicating Together**, December 1997).

Donna points out that you can't keep up with the technology. As soon as you drive your new system off the lot it is obsolete. Something else is waiting that can do the job in a much more efficient way. Donna explains how, when newer versions of software are made that are not compatible with what she is running, it becomes increasingly difficult to keep up with the communication needs of her kids. She simply can't afford the changes.

Donna described how, when her daughters got their devices, she tirelessly trained them to use voice output to make requests and direct their own care. Of course, integration and community involvement was the intended goal. Donna was

heartbroken as she took her kids into the community and she was forced to translate each time the salesperson would look at her and say with a wrinkled brow, "What did she say?" The older versions of synthesized speech were monotone and very hard to understand. They did not give her girls the independence for which they had been hoping. As the newer more sophisticated and intelligible voices became available, Donna saw a big change. Her kids began to become accepted in the community and she saw the total isolation and dependence slowly washing away. She also began to see the fears and prejudices fading. Donna reminds me that voice output is not the *answer* but it certainly contributed a lot to letting her daughters become more accepted in the mall and McDonalds. It made them not so different or intimidating to others who didn't know them.

AAC has certainly changed parenting for Donna. She relies on her kids more. Before Amy and Angel could make their needs known, Donna spent much of her time guessing and worrying that she had interpreted incorrectly. She felt totally responsible for knowing how they were feeling and what they wanted and needed. Amy and Angel now hold the responsibility and welcome it. Now Donna doesn't have to feel guilty about possibly missing what they might want or need or feel. Since they have started to communicate for themselves Donna has seen their true personalities come out. She describes Amy as just like you

and me only with different likes and dislikes. Angel has got lots of spunk and courage. She has learned how to adapt and not be passive. As we ended our conversation Donna mentioned that she feels that nothing in the world gives you more control than communication and that augmentative communication was the greatest blessing that ever came along for her family.

Ruth Harrington of Markham, Ontario, has also seen much growth in the area of augmentative communication. Her daughter Kari is now thirty-one years old and currently lives at Participation House. They have both contributed to **Communicating Together** on many occasions. Ruth describes how for Kari and their family "being in the right place at the right time" was far more than a cliché and certainly more than pure luck. Kari was one of the first to use Blissymbols and had the fortune of having the most dedicated and enthusiastic therapists and teachers. Ruth discusses the excitement and publicity that surrounded the initial stages of using Blissymbolics as an alternative means of communicating. This period in Kari's life brought many positive effects and built her self esteem and confidence. In fact, Kari remembers being shown in a television program because she was attending public school. This, I imagine, was real news at that time. Ruth tells about how this lifted Kari's self esteem and helped build in the motivation for her to attempt other things. Having Blissymbols

to rely on allowed Kari to relax her own attempts at vocalization. Speech then became more functional for her communication within the immediate family. Kari became a good Bliss user and then began to understand and read the text accompanying the symbols. She had the symbols on her boards only for the benefit of her listeners. Ruth explains how wonderful it was to see her learning Blissymbols and literacy skills — using one system to help strengthen the other. She also began to use signs to get her points across and to this day it is a primary mode of communication for her.

Kari uses many modes to communicate. With her mother and her sister she uses her own speech and signs and some finger spelling. To converse with her dad and brother she often uses her Epson voice output device or a small alphabet display. Kari also updates her communication menu books and rearranges the sentences to suit her needs at that time. For telephone conversations, she uses her voice output device. Ruth describes, however, the struggle at times to understand the voice of the Epson over the phone and how they must resort to spelling out words that are not understood. Kari uses the printed output of the Epson to type up notes and messages that help her direct her own care. She uses a computer for journal writing and word processing. Over the years, Kari's communication system has certainly evolved to what it is today — a wide array of high and low technology. Although Kari

has the benefit of technology Ruth points out that her systems are by no means state of the art. Kari would benefit from better access to the internet and e-mail to further her communication opportunities. Ruth describes the efforts of so many who have tried to help and is tremendously grateful. She mentions that in these changing times with cutbacks in services and funding, there are certain realities over which they have no control. Living on a fixed income, she explains they cannot always provide what they would wish, nor can they always give where they would like to, but, they look to the future with hope.

Summing up

In reflecting on all these wise thoughts, as always I feel I have learned more than I could possibly share, in talking to the families who ultimately direct us to the heart of the issues. The things that have stood out as I interviewed these folks begin with the big change of introducing voice output. Although many individuals don't *rely* on voice output and tend to use more low tech methods when in the company of friends, family and familiar listeners, I think the key use of having a *voice* was evident. Kari Harrington needs her *voice* to talk to her mother on the telephone. It was mentioned that for those community situations in which consumers need to be more accepted, that often having a *voice* helps them to fit in, whether that be in kindergarten for Kelly, or at the mall for Angel. Another notable

issue that came to light from our contributors was the change that families experienced in parenting as they could give up the responsibility of guessing communicative intents. Both Donna and Sue showed us the power in a child being able to show and tell their needs, and how it takes the pressure, worry and doubt off the minds of the parents. I found it wonderful to hear of the AAC intervention process beginning so early. Samantha was only two years old when the ball got rolling. Several years ago would AAC have been started at such a young age? I know several individuals who are now in their thirties (Nola and Kari for example) who didn't have the opportunity of exploring AAC until they were school aged or even older. Samantha's reported progress only highlights the importance of getting an early start. After all, communication starts at birth.

As a professional in the field, one of the appealing aspects is how the technology has changed and continues to change to provide a dynamic field that is always interesting. For families, this changing technology only serves to complicate their already complicated and busy lives. Maybe one of the things that draws professionals to the field is drawing families away. Interesting to consider? And the costs? As Donna and Ruth point out the costs of keeping up to date with technology are unreasonable for the average family. How are they to provide opportunities such as surfing the net and e-mailing

new friends across the world without an open pocket book?

The last point I shall make concerns families. We have seen and continue to see the effort they put into trying to implement something more into their busy lives. Sure we need to empower families. They are the most important team members. But they can't do everything. They will burn out! I realize it must be difficult for families to openly discuss their frustrations, but I see how important it is for them to explain their views so that professionals might effect some changes. I think it is hard to know how much involvement is required for each family but, I also think that we need to make it our jobs to find out. We need to ask the questions, "How can we make this easier for you?", "How can we help?" and "Do you want help right now?"

I am glad to have talked to Julie and Keith because they reminded me that everybody has a "frustrating day". Hopefully families and professionals can start to feel comfortable enough to share their feelings, concerns and fears in order to build collaborative relationships that are based on trust and mutual respect. §

Have you moved?

**Please,
send us your new
address.**

Friends Looking Back

NOLA MILLIN



Nola Millin

As I sit in front of my blank blue computer screen with a blinking cursor staring at me, I'm trying to figure out what to write for this issue. Obviously, I have realized this isn't going to be an easy task since I have procrastinated until the last possible moment and I'm past the deadline. In this issue we are trying to compare how things were thirty years ago, fifteen years ago, and what they are like today. My first problem is the fact that I'm thirty something years old. I don't have clear memories of what it was like thirty years ago. I was too busy being a kid to notice the world around me. I knew I was disabled but I definitely didn't know what that entailed. I didn't know about the many challenges I would face just in order to live. I didn't know I would be an AAC User, a consumer, or any of the other labels that have been placed on

me. Nobody told me that in thirty years I would be leading an independent life with the help of attendants, computers, and modern technology. Since I don't know what it was like to be a disabled adult thirty years ago, I asked two friends who do. Both of these friends shared with me what life has been like for them in the past thirty years.

The first individual I spoke to is Dan Frimer, an almost fifty-year-old man with cerebral palsy. He is a wheelchair user and has a speech impairment. His speech is understood by those who know him but Dan often has to repeat himself a number of times before the listener understands him. The other person I spoke to is Lynda Jacko who was featured in the June issue of **Communicating Together**. Lynda has just celebrated her fiftieth birthday. She uses a voice output device for her main communication but, as well, she has a word book and uses facial gestures and verbal sounds to express herself. Lynda and Dan have basically grown up together and they now live in the same building as I do. We tease them about being husband and wife or brother and sister. Either way, Lynda quite often and very effectively puts Dan in his place! In many ways their stories are similar.

Thirty Years Ago

Thirty years ago they lived in a chronic care hospital. As Dan said, "We didn't go out much. We

only got out in order to go to a sheltered workshop. When we did get out, they made us be back around 10:00 p.m." They were told what to do and when to do it. The public talked to them like they were "mentally handicapped." Both expressed that they only went to church if someone took them. Dan said he went about once a year but Lynda said she went twice a year. Churches and other public facilities weren't accessible. There were some cabs that were somewhat accessible. So that is what it was like for Lynda and Dan when they were younger.

Fifteen Years Ago

Now let's go back fifteen years ago. At that point, I had been living on my own for about a year. Our society was beginning to accept disabled people and they were living in some ways as they live today. Our community was probably the first one to have curb cuts since there's such a great disabled population in one area. (There are twenty disabled people in this one building.) Technology was just starting to become available. I relied heavily on an electric typewriter and word board to make my needs known. Life for Lynda and Dan was better, too. They had moved into this building known as A.L.P.H.A. (Apartments for Living for Physically Handicapped Adults) in 1978. Dan summed it up by saying, "When I came here nineteen

years ago, I had no idea what life was like.” They both remember that Handi-Transit (our local para-transit service) made their lives easier but during the first few years the hours of operation were limited. I, too, remember this. I spent a university semester having to take a cab home because I was in a night course. The bus didn’t run past 5:00 on that particular night. For Lynda it was an exciting time, since she got her first voice output communication aid. Lynda said, “I was so excited when I got my first Handi-Voice (roughly twenty years ago), since I could share my feelings especially with my mom and dad.” I can identify with Lynda since fifteen or twenty years ago was when I began working with Dr. John Eulenberg, Director of the Artificial Language Laboratory at Michigan State University, to develop a voice output device for myself. Things were definitely changing but there still needed to be more changes to society. Dan said, “The public was a bit more accepting” (back then). Dan was able to take Handi-Transit to church and I remember Lynda going to church with friends.

Now

It’s now 1997 and times have sure changed. I know in my own life, I depend heavily upon technology. As I stated at the beginning of this article, I use a computer. My computer is my “life line.” (Rob Haaf is probably reading this and killing himself

laughing since he knows I was against computers at one time.) After I have finished writing this article, I will e-mail it to the editors. E-mail has become a great means of communication for me. Also, on my computer there is a device called a phone communicator that allows me to talk on the phone. I have all of the common “toys” — answering machine, fax machine, VCR. I also use a lap-top computer hooked up to a multi-voice in order to communicate in addition to my word board. Technology has made me more independent.

Technology has helped Lynda as well. If you read Lynda’s article in the June issue, you know she uses a computer for written communication and, as already stated, she uses a voice output device. Unfortunately, Dan has never gotten used to technology. He tried a voice output device but he claims he can’t get used to it so doesn’t use it. This irritates Lynda a lot! Dan has a word board that he doesn’t like to use. He says, “Some people understand my speech but few take the time to listen.”

All three of us rely somewhat on Handi-Transit to allow us to lead independent lives. Dan is now a board member of Citizen Advocacy, a member of the Knights of Columbus, and a weekly church goer. Lynda attends her church three times a week. Dan says there is a “95% acceptance in public.” As for myself, I’m a very independent person. I’m involved in

committees, work at a workshop, and I’m an active member of my church. I don’t rely on Handi-Transit as heavily as others because I’m able to transfer in and out of regular vehicles but it’s nice to have a choice of which mode of transportation to use. Dan sums it up by saying, “Life is better now!”

Things have come a long way in thirty years. I admire what Lynda and Dan have accomplished. I can’t wait to see what another thirty years will bring. By then I’ll be the old-timer! §

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Changes in Institutions

COLLEEN McGAFFEY



Colleen McGaffey

*We are delighted to welcome Colleen to this anniversary issue to join us in looking at changes affecting AAC users since **Communicating Together** began. We appreciated so much her involvement as a member of the editorial team between 1991 and 1995. We are glad she was able to take some time from her busy work and family responsibilities to share the perspectives of two residents of Southwestern Regional Centre concerning institutional changes during the past thirty or more years.*

Institutions — the very word makes most people shudder and think of some old horror movie. I wonder why? That has certainly not been my experience in the fourteen years I have worked at Southwestern Regional Centre (SRC). When Nola Millin

asked me to write about institutional life thirty years ago, fifteen years ago and today, two gentlemen, David and Charlie, came to mind. They have lived in institutions throughout that time period. An interview with each gave me a unique opportunity to share stories.

David communicates with speech that is difficult to understand at times. If you listen closely, you soon realize he is quick to tease and there is no mistaking his sense of humour. He has a physical disability which limits his abilities on his left side and he has a developmental disability. He has used a manual wheelchair and now has a power wheelchair as well.

Over Thirty Years Ago

In May, 1959, David moved to Rideau Regional Centre, Smith Falls, Ontario. This was a difficult move both for David and for his family, with whom he remains in close contact. During the time that he lived in Rideau Regional, David and his family were not able to see each other very often due to the distance between Smith Falls and the family home in London, Ontario. David remembers lots of snow and his parents travelling by train to visit him. He lived in a residence with twenty-six boys of different ages. He describes life then as a little rough. Many of the boys were juvenile delinquents and there was no distinction among disabilities.

In 1961, David moved to Southwestern Regional Centre, Blenheim, Ontario. David and his family were happy to live closer to each other. He has fond memories of those days. He helped to feed and take care of the other children and to mop floors. He remembers there were no trees, just farmland. He remembers he didn't like coming here but he got used to it very fast. He enjoyed school, Boy Scouts and trips to places like Niagara Falls. He saw his family every two weeks and for a week in the summer.

Fifteen Years Ago

Fifteen years ago, David remembers working in a workshop sanding tables, woodworking and making flowers for weddings. There were lots of activities and outings. He remembers having fun then. He went home for most of the summer and he was happy.

Over the past fifteen years, David has become an avid photographer. He enjoys going out for walks by himself to take pictures. There are more trees and flowers now. He likes having a variety of jobs and things to do.

Now, David says, "I'm sad all of the time - it's not fun now. I wish SRC would stay open and be like it was. When I hear of homes in the community, I try to stay away. There's nothing to do out there (no work) and I can't go places by myself. I'm sad to see

people leave (counsellors and other residents).” Every time he has a friend, they leave, then he cries awhile.

Fifteen years ago, Charlie worked in the workshop with David. Then a craft store called “Step Ahead” was opened in Blenheim and Charlie enjoyed

working there for ten years making macrame hangers and flowers for weddings. Charlie has missed working there since the store closed. He remembers few people moving out of SRC then. He was still able to walk with a

cane. He had a girlfriend and was happy, involved with his businesses, macrame crafts and back massages. He is president of the residents’ leisure committee. He has a new girlfriend. He says, “I’ll move when I have to but (if given a choice) I’d rather stay here!”

§

Remembering Jane Robinson



Jane Robinson

*Kari Harrington wrote about Jane Robinson and how she dealt with the illness and death of her mother in the June, 1993 issue of **Communicating Together**. This is a tribute written to Jane by Joann McKay, Augmentative Communication Instructor at Southwestern Regional Centre in Blenheim, Ontario. Jane was born Dec. 9, 1942 and she passed away on July 4, 1997.*

God decided long ago that Jane would not speak. He chose to allow her family and friends to give her voice. She did however have words, many words — and she spoke them beautifully. Her raised hands for yes or no, her eyes, her laughter let us know more than most people can ever say.

Her other words were Blissymbols. Given to her in 1974, we found that we had found a way to help her express her dreams, and we were able to provide the voice she never had. She loved us for our ability to understand and she supplied us with information about her life, about her feelings, and about her frustrations. The more she understood, the more symbols she received. She had well over 400 symbols in her precious display. She knew them all and used them well.

I will miss Jane’s words, and I will miss being one of her voices. God decided long ago that Jane would not speak. He chose to give us a rare opportunity, a wonderful gift and an exciting challenge. We were chosen to provide the means for her to communicate. Now God has called her home, where she is, no doubt, talking with the angels using her very own voice. We love you Jane.

We've Come A Long Way — Or Have We?

SUZANNE CLANCY



Suzanne Clancy

As I reflect on my seventeen years in the field of post-secondary education and job readiness training for adults with disabilities, I am both gratified and discouraged by what I see. I am gratified that I have had the opportunity to develop and deliver education and training to over three hundred adults, but I am equally discouraged by the lack of additional programs and permanent funding for such efforts. When I think about how far we have come, I am reminded of my first students who came to me on faith and, with high hopes that together we could make a difference in the way the people with disabilities were viewed in the community and on the job. They were true pioneers, discovering accommodation did not always mean accessibility. I

still remember trying to guide an electric wheelchair around a sharp corner and into a tiny washroom, and “rescuing” a student in a wheelchair from the parking lot because she couldn’t manage the door without assistance. Fortunately, it was a warm fall day and she did not suffer unduly! I also recall the “segregated” cafeteria seating. Although my students were welcome among the general student body, they couldn’t get through the door. Much to their credit, Ontario’s community colleges soon began to make every effort to eliminate many of those early obstacles and to provide fully accessible campuses as funds would permit.

Like many teachers before and, I expect, many to come, I so wish I could bring back those first “pioneers” to enjoy the hard won fruits of their diligence, insight, and patience. Washrooms have been modified, doors have electronic eyes, ramps are in place, fountains and phones are wheelchair accessible, Braille inscription identifies major locations and a small tank could fit through the doors of most cafeterias.

So why, you ask, am I discouraged? I am discouraged because I am beginning to sense a return to the notion that the handicapped members of our community are best served by limiting their opportunity for further education, training, lifelong learning, and meaningful work. Provincial and federal

governments continue to reduce already insufficient levels of funding, forcing the most vulnerable members of our society into an unfair competition for the scarce resources that are offered. If the hopes, dreams, and hard work of all the pioneering students is to continue to bear fruit, communities, agencies, advocates, and people with disabilities themselves, must make their voices heard and demand what is so rightfully theirs — access to the same education, training, and work opportunities as those of their non-handicapped peers. May we live long enough to see this happen! §

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1977-1997, Two Decades: Changes and Challenges

GEB VERBURG



Geb Verburg

In this issue I would like to address changes in technology and attitude. Technology has the aura of having changed enormously. Attitudes towards disability, which also have changed enormously, pose a very different challenge than technology.

Technology

Indisputably, the most noticeable and most touted changes over the past twenty years have taken place in the technology sphere. In AAC one such change took the form of the switch from the provision of custom-made or one-off devices to the provision of off-the-shelf technologies. The second technology change concerns a cluster of issues that have to do with: (1) the rapid rate of change of technology; (2) the compelling nature of new hardware models, new software versions; and (3)

the comparatively slow rate of change of prescribing and funding systems. It also has to do with (4) a dependence on technology and a chasing after the newest, biggest, fastest machine. I think of this cluster of issues as the gap, or the master and slave game, or catching up with Intel.

From "One-off" to "Off-the-Shelf"

Simon Margolis in a presentation at a Rehabilitation Engineering Society of North America (RESNA) '97 Quality Symposium summarized changes and trends in seating technology from 1975 to 2001. With his non-scientific overview Margolis intended to show that the nature of technology prescription has changed dramatically over the last twenty years. These 'data' are important because they apply to AAC technology also. In 1975 about 80 % of all seating systems were custom made or one-off devices. In 1985 about 60% of seating systems were custom designed for individual users while some 20% of systems were adaptations of commercial devices and only 20% of systems were off-the-shelf products. By 1997 these figures had changed to about 15% custom made and 25% adapted commercial products and 60% off-the-shelf or commercial seating technology. Margolis forecasts that custom seating will reduce to less than 10% of all seating systems by 2001 and that

the bulk (80%) of systems will be bought off the shelf. This is an extremely significant change from the point of view of the technology, which is now available to suit the majority of clients. It is also a change from the point of view of the clients who can now much more readily go out and shop for the rehab device they need. Even for service providers it represents a difference in the way they provide services. According to Margolis, the rehab teams in the U.S.A. already have undergone a change towards less professional involvement in the technology provision process. By 2001 he foresees a team consisting of a family (depicted in a downward rushing rollercoaster cart), a funding provider (Scrooge), and a supplier (someone who delivers the boxes).

This trend in technology provision applies to AAC as well as to seating and other rehabilitation technologies. In AAC the trend is very much in evidence and the practice of buying new technology off-the-shelf after which the necessary adaptations are made for individual clients is now very much the way of life. In all, this is a positive change. The availability of off-the-shelf products means that there are commercial products being manufactured for people who are nonspeaking and/or have other disabilities. This means that service can be provided faster,

and maybe in time that people can go to the store and buy the devices they need by and for themselves. Viewed in the best possible light this means that we are approaching the time when consumers are fully empowered, at least where technology is concerned. They could go to the store and buy whatever they need. From a professional's point of view Margolis's future is scary because we know that implementing rehabilitation technology is never as simple as going to the store and picking the things that one needs. And this is where I think one of technology and service provision's greatest challenges lies at this moment.

Masters, Mistresses, and Slaves

Tantalizingly, each new technology (hardware or software) has a little bit more access capability, a few more tricks, an additional curbcut, a new feature that makes the technology useful, for a few more people. And we all accept that this is the way in which technology development should go. The way of progress, the inexorable move from one model to the next — with every new model possessing a new feature labelled a new version, so that 2.2 can follow version 2.1 and so on, like clockwork. We are all used to this dynamic and are conditioned to its predictable progress. My son just walked in and expressed surprise at my sitting behind a Toshiba 1200 without backlit screen, entering this article in Word Perfect 5.1. Toshiba

portables have long since surpassed the thousand series and the most recent word processor software version is 7. something. It is not just affluenza (the disease of wanting to buy the newest and most recent and en vogue products) that drives this technology chasm. Technology continues to change at a most amazing rate. This extraordinary rate of change makes it very difficult to keep up for ordinary mortals including AAC users and the clinicians who work with them. The speech language pathologists also need to keep current on the newest technologies and may end up spending more time learning about the new technology than developing speech therapy strategies.

Another consequence of this progress of technology is a growing gap between new product release and prescription. Assistive technology devices are provided to people who use them for several (sometimes five or more) years until they are due for, or can afford, new devices. Because technology changes so fast there develops a big gap between someone's old machine and their new computer. So far I have not seen any evidence that newer models of software or hardware (including new versions of special access or AAC software or hardware) are easier to use than the older ones. More often the reverse holds true. Because novelty drives sales, product developers will push new

features out before they are bugfree and easy to use. The consequences are that users and therapists spend much more time learning, and more time frustrated with, new equipment that might not work with one or all of the special adaptive tools that AAC users need to employ.

What is still wrong with technology?

On the global scale technology is playing the obsolescence game with remarkable adroitness. Consumers are easily convinced of the need to buy the next version of hardware and software. Each new technology appears necessary and we prove the developers and technology sales people right by buying their offerings. This would not be so bad if the new technologies would actually be easier to use and do more for us. That is, do more than increase the processing speed or the memory or improve the video images we can get (if we are patient enough ... Or, if we only had a fast enough machine, and enough video memory, or if we only ... and so on and so forth). As AAC technology gets more closely intertwined with computer and telecommunication technologies, the technology rat race becomes an integral part of AAC technology provision.

Attitudes

When I started to work for the Blissymbolics project in 1977, the Bloorview MacMillan Centre

was still called the Ontario Crippled Children's Centre. Disability was a disease or a medical condition and people with disabilities were patients. Students with disabilities were not expected to get a job. And, children who were nonspeaking were only beginning to be expected to communicate. Today, in many parts of the world, children with severe disabilities are given the means to be mobile, to manipulate, and to communicate and they are expected to be as independent as they can be. That is an enormous change.

It is time to ask the question from the back seat of the car on this long trip to Equality: "Are we there yet?". The question is relevant, and the traditional reassuring answer: "We're almost there!" does not really apply (yet). In Canada at least, we have been moving at a very nice clip over the past twenty years. Terminology and expectations have changed, understanding has grown, national programs were instituted. R&D grants were made conditional on consumer participation. Empowerment was an oft heard word for a few years. And then ...?

What happened to Empowerment?

In 1992, a conference called *Independence 92* brought together in Vancouver several thousand people with disabilities from all over the world and, as well, representatives from federal and provincial governments. The spirit of the conference was one of hope and accomplishment. It looked like the time had finally come when people with disabilities could aspire to the same things as non-disabled people. What has happened to that spirit? What has happened to the attitude of hope?

Have we lost what was gained in the early nineties? When empowerment became fashionable and politically correct, much ado was made and a number of things were accomplished. But like fashion and politics the views and the tastes have changed. Governments and R&D agencies are now pushing business and industry (industriousness?) as the salvation of the world, and empowerment has, kind of, fallen from grace.

"It's up to you"

It is almost as if the world has decided that people with disabilities have been empowered, that the job is now done, finished, over with. It is now up to the persons with disabilities to make sure that they get what is coming to them. We, that is everyone else, have done our job, we can now go back to making money in earnest because we have empowered people with disabilities. It is back to business as usual. The problem is of course that attitudes do not change like fashion or political agendas. Attitudes run deeper. And while a lot has changed an even greater misunderstanding (or lack of understanding) remains. Yes, there are more rights, and yes, many expectations have changed. I think it will be a while yet, however, before we will fully realize how quickly that beautiful and so very much too short season of empowerment will turn into another, and much longer era of neglect. I very much hope that I am wrong in this sour assessment but this is how things look today. §

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AS COMMUNICATION CHANGES

Changes in Chronic Care

WINKIE SIMPSON

Wilkie Simpson is a clinical nurse manager at Runnymede Chronic Care Hospital in Toronto. She has inspired many people, not only because of her clinical knowledge of how to care for the special and varied physical needs of severely disabled people, but also because of the respect and caring she has for the residents of this hospital.

I was asked by Alda Steprans to write about the changes that I have witnessed in the last twenty years for people who are hospitalized with chronic illness. At first I thought that there would be a series of big events that would show landmark changes over the years. Upon reflection, however, the changes have been gradual but cumulative. Nurses who have worked in this area since the 70's will tell you that the patients in chronic care today are much sicker (heavier care) than they were twenty years ago. The most obvious change from then to now is *who*, that is who are the patients and who is taking care of them. A person who has a problem that is more responsive to treatment, is much more likely to be cared for in the community. Today's approach in chronic care is *Interdisciplinary Care* whereby a team of professionals works together to develop care plans for individuals. This makes so much

sense because the illnesses are complex and there is a much broader approach with a team.

Twenty-five years ago, a patient was getting good care if they were nice and clean and well fed. Quality of life issues often seemed to focus on the need of the organization rather than patients' needs. The current approach is focused on the individual's needs. Quality of life for people is a very personal thing. For individuals with illnesses that do not lend themselves to cure, their quality of life issues often revolve around making some specific aspect of their life better. For example, the chair that is chosen for a person will be considered from a perspective that will respond to that person's strengths and abilities, as well as considering comfort, safety and ease of maneuverability.

Different hospitals have become specialized in taking care of a specific patient population. This results, for example, in people who have had a stroke or who have Huntington's disease or multiple sclerosis having the support of professionals with expertise in taking care of people with these problems. When someone can no longer speak after a stroke they will need hours of specialized speech therapy and training with a communication device in order to help them maintain contact with others. Any communication that helps that avenue open up is invaluable to

the individual who has lost the ability to speak.

We see people in chronic care now who were not there twenty years ago, such as people with Huntington's disease. In the eighties, we knew very little about the disease and we had to learn as we went along. There has been active research into this and other neurological diseases with a major breakthrough coming in 1993, when the HD gene was discovered. This has given great impetus to further research and hope for a treatment and eventually, a cure. The research has given us specific information that helps us to understand the disease better, namely, that a specific part of the brain is under attack (the caudate nucleus) and this affects the person in three distinct areas — their motor skills, their cognitive abilities and their emotional health.

It becomes a major challenge for family members and caregivers to achieve therapeutic care at times. Quite often, our goal is to help the patient to cope with stress. For some, independent mobility may be the issue. Quite clearly, the challenge will be highly individualized and the care plan will be customized for each patient. Changes are occurring daily in the health care system. We must be vigilant that care giving is the focus, strengths are maximized for individuals, and support is there when it is needed.

The views of two residents



Audrey McGee

I don't feel sick, but I did when I first came to live in this chronic care hospital. Then, I couldn't swallow. I had a tube in my stomach through which I was fed. I couldn't talk. I couldn't move myself. With time I learned how to eat, communicate and use my left arm to move myself around. Although I am paralyzed on my right side and can't really talk, I don't consider myself sick.

My needs are still complex. Because I can't move the right side of my body, I can't take care of myself. I can't walk, but I can use my wheelchair independently using my left hand. Eating has been difficult because the nerves to my swallowing muscles were injured when I had the stroke. I need my food specially prepared so that I don't choke. The food here is just right for me. It tastes pretty good and there is lots of it.

Communication also presents its problems. I can sometimes make myself a little understood when I speak. I use the communication board fairly well, but do have some problems with my spelling. For the last month I have had the use of a talking computer, which has been

just wonderful! Sadly, I have to give it back in two weeks. It has been so good to have a voice!

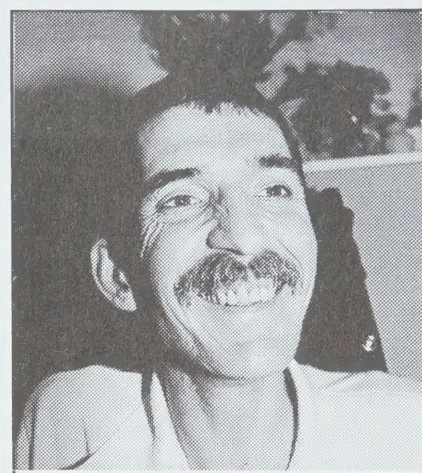
I like the staff here much more than at the other hospitals I have been in. They are just like family. Some of the nurses are experts in caring for me and many others try to give good care. The expert nurses really *care*. I can feel who truly cares about me, who anticipates what my needs are and does all the little things for me that make life pleasant. There are many experts in the hospital. I feel confident when they're around.

I use all the departments in the hospital — speech therapy, physio and occupational therapies, nurses, doctors, the dietary staff, maintenance and housekeeping. Everyone works together well.

My needs are fairly well taken care of, but I think they could be even better met with more nursing staff around — more people to just talk with and help with the little things. People are often rushed and busy.

Even though I can communicate now, I still often feel isolated because I can't talk, and using the other communication methods takes time. I'm definitely treated as an individual and receive the care I need. Everybody talks to me.

I'm not afraid of the changes in the health care system. Although they are closing the hospital I live in, they have said they would be building a new place for us. I have hope that the good care I get will continue and maybe even improve.



Steven Hanlon

My disease is Huntington's. The care I am getting in this chronic care hospital is great! The nurses make me feel good. It's part of their job. I love the nurses. I'm happy with everyone. I also like Lois, who works in the Activities Department. She lets me work on the computer.

My needs are very complicated. Eating is a problem because I have difficulty swallowing. I need lots of calories because of the jerky movements my body is always making. I need food that has a special consistency so that I don't choke. I also love food that tastes good. The food in this hospital is good. I have an ulcer now so I can't drink any more beer, coffee or tea. Before I had my ulcer the nurses thickened these with a special powder so that I could drink them without choking.

My brain is also a problem. It's sure unique. I'm crazy like a devil! I love to laugh and I like people around me who are funny. My muscle coordination is very poor. I can't walk on my own and it's hard for people to understand me when I talk. I can walk really far now when two people help

support me. I can also ride the special bike they have at the hospital. I love to ride that bike! I can't feed myself any more, but I can use a special non-spillable cup. I can push myself around in the wheelchair. I make the best of it.

The people who care for me are very good. They know what they're doing and have lots of good ideas to help me maintain my independence, like using the computer and the exercises I get in speech therapy. I can still talk (even though it's hard for many people, who don't know me, to

and practice). A few months ago I suddenly could talk a lot more clearly again. I think the change was due to a change in my medication.

I go to speech therapy, physio therapy, and occupational therapy often and to the activities department every day. Of course, nursing, the doctors, the dietary staff and pharmacy are involved in my care daily. Everyone seems to work together well.

People do focus on my needs. When another resident in my room was bothering me, I asked to be moved, and I was. I

feel that patients are the most important part of the health care system and here, we are treated as important.

I am not worried about all the changes in the health care system. Nothing much has changed here, yet. They were going to close the hospital I live in, but now they are talking about building a new long-term care facility. I am hoping the new one will be just as good. I have lots of faith in the people in the health care system. §

PAUL'S PLACE

Looking at Change Dance Across the Stage

PAUL MARSHALL



Paul Marshall

Have you ever noticed that life can be a beautiful dance across the stage? "Paul, you are starting to lose it — what does dancing have to do with looking at change?" Well, I don't know, but it sounded a good way to start this column. For the last fifteen years I have been

dancing in what can be called the "adulthood dance". Meet my dance partner. Her name is: Ms. Change. She is always with me. I know her, but I don't. Her presence is felt wherever I go and in whatever I do. Do I get used to her ways, you might ask. No, she always keeps me on my toes.

Change has been good for me over the past fifteen years. Sure there were times when I felt crushed by the circumstances that she gave me, but I would be fooling myself if I said that I didn't grow from these down periods. If we are breathing, then we must feel effects of her. Learning how to dance with Change may mean that we are on our way to mastering life which is forever developing in different ways.

Sometimes Change seems bigger than life itself. We must see our own lives as a very small part of history. We often have the underlying belief that history and the world moves around our being, but it doesn't. Our lives are just a season compared to the life span of time itself. In a real way, Change is everyone's dance partner. She has outlived everybody and will outlive generations to come. She has a master plan and uses individuals throughout history to bring it into being.

Change has been very active in my life and, I deeply believe, in both the field of AAC and in the disabled community.

The disabled community has seen major changes with regard to being accepted and being

integrated into the main stream of society. I regret that in some parts of the world this is not yet the case.

The major change that comes to the forefront for me is, the huge impact of the super telecommunication highway, both in the general world and in the AAC world. This monster is moving into every sector of the twenty first century. It is a time when words like: faxes, email, internet, home pages and world wide web are a daily part of our language. It is a time where the home office is an option for many individuals. It is great for anyone like myself who has been blessed to have the opportunities to get the skills and the equipment to work from my home. For myself, the technology which has been developed over the past fifteen years has made a huge impact. A major part of what I do in the AAC field is done from my home via my computer. There is no doubt without having email, access to the internet, voice output and my word prediction program, my world would be very different. With the technology that I have been blessed to have at my finger tips, I can give back and be a source of help.

I have a few concerns about this monster, however. This spring my sister-in-law was telling me that my nephew had to stay in over his break to type his essay because he didn't have it typed out on disk. My brother and my sister-in-law are a normal middle-class family who are just getting into the computer age — they have an old so called “out-of-date” computer to learn on. My

nephew who was in grade four felt the effects that this computer age is bringing into society. The effects of removing access to information from people who might not have the money or the knowledge that it takes to access and keep up with the forever changing computer age are becoming more evident. My fear is we are right on the edge of creating a greater gap between the “have” and the “have nots”.

Are we travelling too fast? Are we letting Ms. Change rule and lead us to a place where individuals will be left behind because they aren't capable of keeping up-to-date with new equipment and the overwhelming resources out there? Are we at the crossroads as a society of running ahead before we should? I am quite concerned in the AAC field and in the general world. We may have moved to the point of believing that if a solution is not quick, simple and highly technical then it is not worth doing or having. We are on the edge of a world where if every computer stops working, we would become a generation with no way of writing or communicating. We seem to have forgotten the “pencil lifestyle” where we knew how to function with less. We are also at a point morally, where we are being brainwashed into thinking the super highway way of life is where it is at, but most of us really don't like it. Are we at the point where the snowball of Change is too big for us to handle or are we just content to sit back and make sure that our own life

and lifestyle are not in question. On the other hand, do we, do I, have the moral sense, even if it is painful to take a stand, to say, “hold it, let's review this and maybe alter what we are doing”?

As we dance our dance, especially within the computer age, it is important that we don't get ourselves trapped by new technology. Every time we turn around there is something new that changes how we operate in the forever changing computer world. Change is always at our door step, but when it comes to the computer age, we have many options. It is up to us how we want or choose to use them. §

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